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A randomized trial to evaluate an education programme for patients and carers after stroke

Jane Smith, **Anne Forster** and **John Young** Bradford Elderly Care and Rehabilitation Research Department (BECARRD), St Luke's Hospital, Bradford, UK

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Objectives: To evaluate the effectiveness of an education programme for patients and carers recovering from stroke.
Design: Randomized controlled trial.
Subjects and setting: One hundred and seventy patients admitted to a stroke rehabilitation unit and 97 carers of these patients.
Interventions: The intervention group received a specifically designed stroke information manual and were invited to attend education meetings every two weeks with members of their multidisciplinary team. The control group received usual practice.
Measures: Primary outcome was knowledge of stroke and stroke services. Secondary outcomes were handicap (London Handicap Scale), physical function (Barthel Index), social function (Frenchay Activities Index), mood (Hospital Anxiety and Depression Scale) and satisfaction (Pound Scale). Carer mood was measured by the General Health Questionnaire-28.
Results: There was no statistical evidence for a treatment effect on knowledge but there were trends that favoured the intervention. The education programme was associated with a significantly greater reduction in patient anxiety score at both three months ($p = 0.034$) and six months ($p = 0.021$) and consequently fewer 'cases' (Hospital Anxiety and Depression Scale anxiety subscale score ≥ 11). There were no other significant statistical differences between the patient or carer groups for other outcomes, although there were trends in favour of the education programme.
Conclusion: An education programme delivered within a stroke unit did not result in improved knowledge about stroke and stroke services but there was a significant reduction in patient anxiety at six months post stroke onset.

Introduction

The provision of accurate, timely information and advice is a recommended component of service provision in stroke.[1,2] However, patients and their families report dissatisfaction with the quantity and quality of the information they receive such that their understanding of stroke, its consequences and the available support is poor.[3–7]

A systematic review of information provision for patients and carers after stroke[8] found little evidence for the effectiveness of information provision by leaflets and booklets[9–13] although there was some evidence that information provided in educational sessions improved knowledge.[14–16] It

Address for correspondence: Jane Smith, Department of Health Care for the Elderly, St Luke's Hospital, Bradford BD5 0NA, UK. e-mail: stroke.research@bradfordhospitals.nhs.uk

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is likely therefore that the method of delivery of information is as important as its content. In England, the importance of a greater patient-focus to services has been emphasized.[17] Integral to such an approach is effective communication with the patient and their families to ensure that they have a good understanding of their illness, possible problems and realistic goals.[1] We developed an education programme for patients and carers recovering from stroke focused around the process of rehabilitation goal setting. It aimed to address individual patient and carer information needs and increase patient involvement in the rehabilitation process, both in hospital and post discharge. The effectiveness of this intervention was tested in a randomized controlled trial.

Method

Setting and participants

The setting for this study was a stroke rehabilitation unit in a district general hospital in a north of England metropolitan city. Patients with a diagnosis of acute stroke are admitted initially to general medical or care of the elderly wards and subsequently transferred to the stroke rehabilitation unit. The admission policy of the stroke unit encompasses patients of any age and stroke severity. The hospital trust responsible for the stroke unit was rated in the top third of the three National Sentinel Audits for Stroke in 1998, 1999 and 2001.[18,19] Ethical approval for the trial was obtained from the local research ethics committee.

All patients admitted to the stroke rehabilitation unit between 1 March 2000 and 31 January 2002, together with their carer (a person living with the patient), were considered for inclusion in the study. Patients were approached for study participation within three days of their transfer and screening tests for aphasia (shortened form of the Frenchay Apahsia Screening Test)[20] and cognitive impairment (Hodkinson Abbreviated Mental Test)[21] were completed. Patients who had receptive aphasia, cognitive impairment or did not understand English were excluded if they did not have a carer. If a patient was unable to give consent, written assent was sought from their carer and in this circumstance the carer was the main focus of the intervention. The baseline assessment comprised a structured interview that covered demographic details, pre-stroke function, age on leaving full-time education and previous support and services received. The stroke subtype[22] was obtained from the stroke physician. The Barthel Index score[23] on admission to the stroke unit was recorded and a stroke knowledge questionnaire (described under outcome measures) and the Hospital Anxiety and Depression Scale[24] (HAD) were completed by all patients who were capable. Carers were asked to complete the stroke knowledge questionnaire and the 28-item General Health Questionnaire[25] (GHQ-28).

Randomization

Patients were randomly allocated to the education programme or usual care using random length restricted permuted blocks (block lengths of 2, 4 and 6). Patients were stratified by Barthel Index scores of 0–4; 5–9; 10–14; 15–19,[26] presence of aphasia (score below 15 points using the shortened form of the Frenchay Aphasia Screening Test), and presence of a carer. Concealed randomization was achieved using sealed, numbered, opaque envelopes kept in a locked separate location by an independent research assistant who carried out the randomization and conveyed patient allocation information to the stroke unit co-ordinator. All patients received usual practice care from the date of admission to the stroke unit until they had been randomized to a study group.

Intervention

Patients and carers randomized to the education programme were given a copy of the Stroke Recovery Programme manual and invited to attend specifically convened meetings with members of their multidisciplinary team. The Stroke Recovery Programme manual was specifically devised based on the information needs reported in qualitative stroke studies[7,27,28] and further informed in its development stages by iterative qualitative interviews with 30 patients and carers. The manual contains information about the causation and consequences of stroke, stroke recovery, financial benefits, relevant services and has a specific section for carers. It aims to facilitate patients and carers adjustment to stroke by enhancing their knowledge of stroke, the recovery process, the rehabilitation programme

and availability of services and financial benefits. The Stroke Recovery Programme manual was supported by pre-arranged review meetings every two weeks with their multidisciplinary team (doctor, nurse, physiotherapist and occupational therapist). Meetings were held in the ward dayroom and were scheduled to last approximately 20 minutes. Guidelines were developed for use by the rehabilitation teams to ensure coverage of the key topics included in the Stroke Recovery Programme manual and a record of matters discussed was completed following each meeting. The intention of the meeting was to provide background information about stroke, discuss patient's progress, answer specific questions and develop shared rehabilitation goals. The agreed goals were recorded in the Stroke Recovery Programme manual which was retained by the patient. Patients or carers allocated to the intervention group but unable to attend a meeting due to early discharge were invited to meet with the consultant in the outpatients clinic.

Patients in the control group continued to receive usual practice. Members of the stroke unit multidisciplinary team were free to discuss aspects of treatment and respond to any specific queries. A folder of information about stroke causation, consequences and recovery previously devised by the ward staff and a variety of Stroke Association leaflets were available and prominently displayed within the stroke unit.

Patients and carers were followed-up by home visits at three and six months post stroke by a research nurse who was blinded to the allocation group. Carers of patients who had died during the course of the study were not contacted.

Outcome measures

The primary outcome was knowledge of stroke measured by a questionnaire developed for this study. The questionnaire incorporated questions used in previous similar studies,[12,15] supplemented by new items designed to increase relevance (see Appendix 1). Both patient and carer completed the questionnaire and, within each patient–carer unit, the results report the patient knowledge score when available, or the carer knowledge score if the patient was aphasic, cognitively impaired or non-English speaking, or had been unable to complete the questionnaire for any other reason.

Secondary outcomes were physical and social function (Barthel Index, Frenchay Activities Index[29] (FAI)), handicap (London Handicap Scale[30] (LHS)), patient mood (HAD), carer mood (GHQ-28) and patient and carer satisfaction. Satisfaction measurement was based on specific stroke instruments,[31,32] with modifications used in previous studies.[15,33,34] If the patient had not been discharged from the stroke unit at the time of the three-month assessment, the LHS and the patient and carer satisfaction questionnaires were not completed. Proxy responses for the LHS, the FAI and the Barthel Index were obtained from the carer for patients who were unable to respond themselves. We also recorded post-discharge contacts with health and social care professionals and services, and take up of financial benefits.

Power calculation

Data were not available from the stroke knowledge questionnaire from which to calculate a sample size. Sample size was therefore calculated using the LHS[30] as a measure for the secondary outcome of interest and for which published variance data was available. Based on early work[30,35] a difference of eight points between each of the groups was anticipated. Using the nomogram of Day and Graham[36] it was calculated that for a trial power of 90% and significance level of 0.01 a sample size of 65 patients per group would be required.

Analysis

Statistical summaries and plots were performed using the software SPSS version 11.0.0 on an intention-to-treat basis using the Mann–Whitney *U*-test for the between-group analyses. Additionally, the number and percentage of 'cases' of patient anxiety and depression (HAD subscale score ≥ 11) and carer emotional distress (GHQ-28 cut-off 4/5) were summarized. Odds ratios with 95% confidence intervals were calculated to analyse responses to individual questions of the stroke knowledge and the satisfaction questionnaires. For post-discharge contact with health and social care professionals and services, and take-up of financial benefits, the number and percentage of patients were tabulated by treatment group.

Results

Three hundred and fifty-three patients were admitted with acute stroke during the study period and 170 patients were recruited: 86 randomized to usual care, and 84 to the education programme. One hundred and nine of the recruited patients were living with a carer and 97 of these (intervention = 49; control = 48) agreed to participate in the study. The main reasons for nonrecruitment were refusal and patients with aphasia, cognitive impairment or non-English speaking who had no carer available (Figure 1). Baseline characteristics (Table 1) were similar in the two groups other than

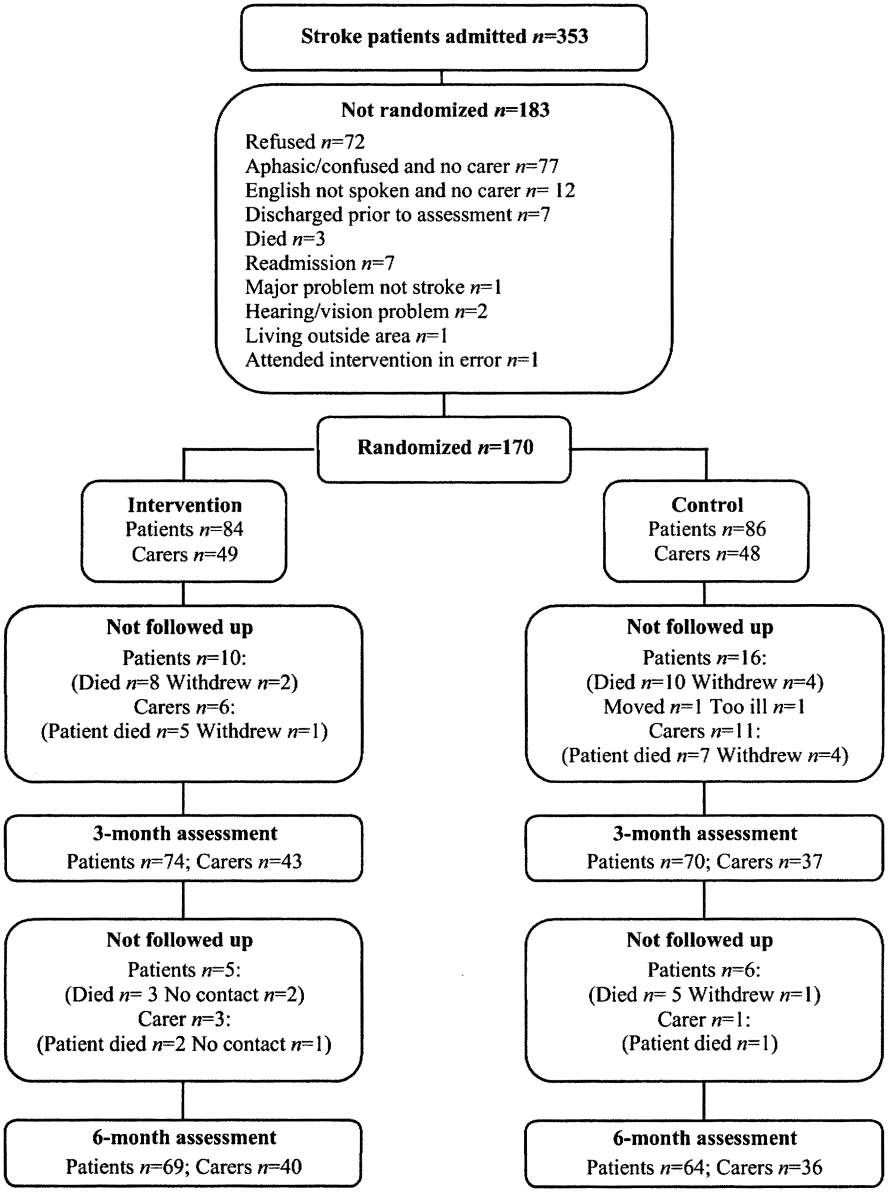

Figure 1 Flowchart of patients and carers during the course of the study.

slightly more men and fewer South Asians in the intervention group, and slight differences in the stroke subtypes.

Twenty-six patients died during the study (intervention = 11; control = 15) and a further 11 patients did not complete the study (intervention = 4; control = 7), seven withdrew; one moved out of the area; one was recruited in error; and two could not be contacted after the three-month assessment. Thus, 133 patients (intervention = 69; control = 64) and 76 carers (intervention = 40; control = 36) completed the final assessment (Figure 1). Of those randomized to the intervention group, 69 (82%) attended at least one goal-setting meeting (median 2 range 1–5) and one patient and their carer met with the consultant in the outpatient clinic.

Table 1 Characteristics of study participants

	Intervention	Control
Patient	(*n* = 84)	(*n* = 86)
Median age, years (range)	75 (31–91)	74 (50–92)
Female (%)	39 (46)	45 (52)
Living alone (%)	30 (36)	31 (36)
Previous stroke (%)	14 (17)	14 (16)
Stroke classification (%)		
Lacunar syndrome	26 (31)	24 (29)
Partial anterior circulation syndrome	20 (24)	26 (31)
Total anterior circulation syndrome	36 (43)	26 (31)
Posterior circulation syndrome	2 (2)	8 (9)
Not known	0	2
Pre-stroke Barthel Index	20 (12–20)	20 (5–20)
Median length of stay, days (range)	36 (3–108)	33 (4–149)
Discharged to own home (%)	55 (65) (*n* = 78)	56 (65) (*n* = 74)
Median age left education, years (range)	14 (10–18)	14 (14–19)
Carer	(*n* = 49)	(*n* = 48)
Median age, years (range)	65 (27–85)	67 (23–85)
Female (%)	32 (65)	24 (50)
Spouse/partner (%)	36 (73)	34 (71)
Median age left education, years (range)	15 (13–22)	15 (14–23)

Knowledge of stroke and services (Table 2)

There was little change in knowledge scores between baseline and six months for either group (intervention group median change 1; control group median change 0; $p = 0.24$). At both three and six months there were no significant differences between the intervention and control groups, although there was a trend for improved scores in the intervention group. When the odds ratios (OR)

Table 2 Knowledge score at baseline, three and six months

	Intervention (*n* = 84)			Control (*n* = 86)		
	Baseline	3 months	6 months	Baseline	3 months	6 months
Patient/carer knowledge[a] (score range 0 → 17)	(*n* = 79)	(*n* = 70)	(*n* = 65)	(*n* = 82)	(*n* = 62)	(*n* = 63)
Median (range)	11 (5–16)	11 (4–16)	12 (3–17)	10.5 (3–16)	11 (4–16)	11 (0–16)
Median change from baseline (range)	–	1 (−5 to 6)	1 (−5 to 7)	–	0 (−7 to 5)	0 (−9 to 7)
Patient knowledge (score range 0 → 17)	(*n* = 54)	(*n* = 47)	(*n* = 47)	(*n* = 59)	(*n* = 47)	(*n* = 45)
Median (range)	10 (5–16)	11 (6–16)	11 (3–16)	10 (3–15)	11 (4–16)	11 (0–16)
Median change from baseline (range)	–	1 (−4 to 6)	1 (−5 to 7)	–	0 (−7 to 7)	0 (−9 to 8)
Carer knowledge (score range 0 → 17)	(*n* = 44)	(*n* = 41)	(*n* = 36)	(*n* = 43)	(*n* = 31)	(*n* = 34)
Median (range)	11 (7–15)	12 (4–16)	13 (7–17)	11 (6–16)	11 (6–15)	12 (4–16)
Median change from baseline (range)	–	1 (−5 to 8)	1 (−5 to 8)	–	1 (−6 to 6)	1 (−7 to 8)

[a]Patient knowledge score used when available, or carer knowledge score if the patient was not able to complete the questionnaire.
→ denotes worst score to best score.

for the individual questions were inspected, 14/17 question responses for the patients and 12/17 question responses for the carers favoured the intervention group at six months. However, the confidence intervals (CI) were wide and only two questions were significantly different. Question 12 ('a stroke may affect personality and mood') was answered correctly by 43/47 (91%) patients in the intervention group and 32/45 (71%) patients in the control group (OR 4.37, 95% CI 1.30–14.65). Question 15 ('it is possible to have help with both domestic and personal care') was answered correctly by 30/36 (83%) carers in the intervention group and 19/34 (56%) in the control group (OR 3.95, 95% CI 1.30–11.95).

Secondary outcomes (Table 3)

There was a significantly greater reduction in the HAD anxiety score in the intervention group at both three months (intervention group median change −1.5; control group median change 0, $p=0.034$) and six months ($p=0.021$) and

Table 3 Summary of secondary outcomes at baseline, three and six months

	Intervention ($n=84$)			Control ($n=86$)		
	Baseline	3 months	6 months	Baseline	3 months	6 months
Patient						
Hospital Anxiety and Depression Scale	($n=51$)	($n=49$)	($n=50$)	($n=57$)	($n=45$)	($n=43$)
Anxiety (score range 21→0)						
Median (range)	8 (1–21)	7 (0–15)	7 (0–15)	7 (0–16)	7 (0–21)	7 (0–19)
'Cases' (score ≥11)	35%	10%	16%	25%	24%	33%
Median change from baseline (range)	–	−1.5* (−14 to 16)	−3† (−11 to 16)	–	0* (−13 to 10)	−1† (−12 to 13)
Hospital Anxiety and Depression Scale	($n=51$)	($n=49$)	($n=50$)	($n=57$)	($n=45$)	($n=43$)
Depression (score range 21→0)						
Median (range)	7 (0–21)	6 (0–15)	6 (0–20)	7 (1–20)	6 (0–19)	7 (1–21)
'Cases' (score ≥11)	22%	10%	10%	21%	20%	26%
Median change from baseline (range)	–	−1 (−12 to 11)	0 (−11 to 13)	–	−1 (−11 to 14)	0 (−10 to 11)
Barthel Index (score range 0→20)	($n=84$)	($n=73$)	($n=69$)	($n=86$)	($n=69$)	($n=64$)
Median (range)	6 (0–17)	14 (0–20)	15 (0–20)	6 (0–17)	13 (1–20)	15 (0–20)
Median change from baseline (range)	–	6 (−5 to 17)	7 (−13 to 17)	–	5 (−5 to 20)	5.5 (−9 to 19)
London Handicap Scale (score range 0→100)		($n=65$)	($n=66$)		($n=57$)	($n=63$)
Median (range)	–	57 (9–90)	59 (20–94)	–	54 (25–95)	57 (12–84)
Frenchay Activities Index (score range 0→45)		($n=72$)	($n=68$)		($n=69$)	($n=64$)
Median (range)	–	1 (0–30)	5 (0–32)	–	0 (0–23)	3 (0–33)
Carer						
General Health Questionnaire–28 (score range 28→0)	($n=44$)	($n=41$)	($n=37$)	($n=42$)	($n=31$)	($n=33$)
Median (range)	7.5 (0–24)	7 (0–24)	8 (0–27)	4.5 (0–21)	8 (0–25)	9 (0–24)
Median change from baseline (range)	–	0 (−10 to 24)	1 (−10 to 24)	–	0 (−8 to 17)	1 (−20 to 15)
'Cases' (cut off 4/5)	59%	59%	62%	48%	61%	70%

*$p=0.034$; †$p=0.021$.
→ denotes worst score to best score.

Table 4 Service use and receipt of benefits at baseline and six months

	Intervention		Control	
	Baseline ($n=77$) *n* (%)	6 months ($n=64$) *n* (%)	Baseline ($n=77$) *n* (%)	6 months ($n=61$) *n* (%)
Contact with:				
Social worker	1 (1)	20 (31)	2 (3)	19 (31)
Community nurse	12 (16)	36 (56)	7 (9)	32 (52)
General practitioner	37 (48)	60 (94)	37 (48)	50 (82)
Therapist	1 (1)	47 (73)	0	34 (56)
Chiropodist	15 (19)	29 (45)	14 (18)	23 (38)
Receipt of:				
Home support	5 (6)	18 (28)	3 (4)	20 (33)
Day centre attendance	6 (8)	8 (13)	1 (1)	3 (5)
Rehabilitation centre	1 (1)	2 (3)	0	1 (2)
Receipt of financial and mobility benefits:				
Disability/mobility allowance	5 (6)	10 (16)	10 (13)	15 (25)
Attendance/carers allowance	10 (13)	21 (33)	9 (12)	15 (25)
Invalidity benefit	0	2 (3)	1 (1)	2 (3)
Blue badge scheme	7 (9)	27 (42)	13 (17)	20 (33)

consequently fewer 'cases' (intervention group eight 'cases' at six months, control group 14 'cases'). There was no evidence of a treatment effect on HAD depression scores. Carers did not differ in GHQ-28 scores. There were no significant differences between patients in the intervention and control groups for the Barthel Index, the LHS or the FAI.

There were generally high levels of satisfaction expressed by both groups but the odds ratios for the individual satisfaction questions favoured the intervention group with higher satisfaction for 10/16 questions at both three and six months for the patients, and 11/13 questions at both three and six months for the carers. However, the confidence intervals were wide and only one patient question at three months, and two carer questions at six months were significantly different. At three months 34/39 (87%) of patients in the intervention group were satisfied that things were well prepared for their return home compared to 20/31 (65%) of those in the control (OR 3.75, 95% CI 1.14–12.33). At six months carers in the intervention group were more satisfied with the amount of information they had received about allowances (intervention 27/35 (77%); control 16/32 (50%) OR 3.38, 95% CI 1.18–0.65). They were also more satisfied and with the amount of contact they had with the hospital after discharge (intervention 27/34 (79%); control 17/32 (53%) OR 3.40, 95% CI 1.15–10.05).

There was a slightly higher post-stroke contact with professional staff, use of services, and uptake of benefits in the intervention group (Table 4).

Discussion

Educational sessions have previously been shown to improve knowledge about stroke,[14,15] more so than by information provision.[8] In this study, we developed a user-focused educational intervention delivered in an individualized manner within a stroke unit. Although there was a slightly greater stroke knowledge improvement in those who received the intervention, there was no statistical evidence of a treatment effect. It is possible that there was an improvement in stroke knowledge but that we failed to detect it. We were unable to identify a suitable measure of stroke knowledge and a questionnaire, based on instruments used in previous similar studies,[12,15] was developed and this may have lacked sensitivity and reliability. Moreover, because we had no prior results from

the bespoke knowledge questionnaire, it was not possible to calculate a sample size estimate and it is likely that the trial was underpowered to demonstrate a significant difference in knowledge. This is reflected in the wide confidence limits for the odds ratios of the individual knowledge questions, the majority of which showed trends in favour of the intervention.

Another reason for the limited effects of the intervention on stroke knowledge might be through a high level of background care, including tutoring of stroke information, on the participating stroke unit. However, it is of interest that there was little discernible change in the knowledge scores for either group indicating no apparent knowledge gain during their stay on the stroke unit.

The limited stroke knowledge improvement might also be attributed to patient difficulties in assimilating and retaining new information due to memory difficulties. It has previously been reported that acute stroke disturbs the ability of patients to learn new material and that this is still apparent in a significant number of patients at three and six months after stroke.[37] However, the fact that there was also little improvement in carer knowledge indicates that it is unlikely that this factor had a significant influence.

Information cannot be effective if it is not received. In a previous study 58% of patients failed to attend the educational sessions provided.[15] Conversely, in our study levels of participation were high with 82% of those randomized to the intervention attending the multidisciplinary team meetings. Care was also taken during the development of the Stroke Recovery Programme manual to ensure that it was accessible to people with a wide range of educational abilities and guidelines were used during the fortnightly meetings to ensure topic coverage. Patients and carers were not questioned about their use of the Stroke Recovery Programme manual as this would have unblinded the assessor and therefore the extent to which the written information provided in the manual was read is unknown.

An important limitation of the study was the unavoidable contact and associated intervention contamination between the two groups of patients and relatives during the inpatient period. It is also possible that the trial may have raised the profile of information provision within the unit. The multidisciplinary team was free to answer any queries by those in the control group and, as they were aware of group allocation, may have consciously or unconsciously provided additional information. These confounding factors would have been in the direction of reducing the measured effectiveness of the trial.

A positive finding of this study was that patients receiving the education programme were found to be significantly less anxious at both three and six months. The provision of information in a variety of formats has been reported to reduce anxiety in other conditions.[38,39] Other stroke studies have provided some evidence of an association between information and education provision and depression but an association with reduced anxiety has not previously been demonstrated.[11,16] The explanation for the observed effect on anxiety may lie in a combination of two factors.

First, a limitation of simple information provision is that it may not be sufficiently individualized or may provoke as many questions as it answers. Studies of patient education in Parkinson's disease and arthritis have reported that personalized information leads to better quality of life.[40,41] This was addressed in our intervention within structured multidisciplinary team meetings where individualized information, advice and reassurance was provided. Rehabilitation goal setting was an integral component of the meetings and there is some limited evidence that client-centred goal setting provides benefits in terms of reduced anxiety in stroke patients.[42]

Secondly, the first few months after discharge from hospital can be difficult for both patients and

Clinical messages

- An education programme for stroke patients and carers was developed and evaluated.
- There was no statistical evidence for a treatment effect on knowledge but there were trends that favoured the intervention.
- The education programme was effective in reducing patient anxiety in the early months following stroke.

carers. The need for information and support in the first few months after discharge from hospital has been well documented but may not, however, always be readily accessed.[43–45] The uncertainty stemming from this has been identified as a source of anxiety for both patients and carers after stroke.[46] The trend to greater use of some post-stroke services by the intervention group suggests that the Stroke Recovery Programme manual might have been used as a reference source and so contributed to reduced anxiety.

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Appendix 1 – Knowledge of stroke and stroke services questionnaire

Please read the following statements. Tick one box for each question.

	True	False	Don't know
1) A stroke is caused by damage to the brain.	☐	☐	☐
2) A stroke is the same as a heart attack.	☐	☐	☐
3) Effects of a stroke depend on which part of the brain is affected.	☐	☐	☐
4) Brain cells which are affected by a stroke may not work again.	☐	☐	☐
5) Most recovery occurs in the first few weeks.	☐	☐	☐
6) Physical, mental, or sexual activity will increase the likelihood of a further stroke.	☐	☐	☐
7) Squeezing a ball can get your hand working again.	☐	☐	☐
8) Therapy can help you move your arm and leg again.	☐	☐	☐
9) A speech therapist teaches you to get in and out of bed.	☐	☐	☐
10) Feelings of frustration are a normal reaction after stroke.	☐	☐	☐
11) Depression is common following stroke.	☐	☐	☐
12) A stroke may affect personality and mood.	☐	☐	☐
13) Flying should be avoided after a stroke.	☐	☐	☐
14) Welfare benefits are provided to everybody who has a stroke.	☐	☐	☐
15) It is possible to have help with both domestic and personal care.	☐	☐	☐
16) Home adaptations are provided free of charge to everyone who has a stroke.	☐	☐	☐
17) A social worker can give advice on welfare benefits.	☐	☐	☐